

## Improving access to care for people who inject drugs: qualitative evaluation of Project ITTREAT - an integrated community hepatitis C service

Article (Accepted Version)

Phillips, Clare, Schulkind, Jasmine, O'Sullivan, Margaret, Edelman, Natalie, Smith, Helen E, Verma, Sumita and Jones, Christina J (2019) Improving access to care for people who inject drugs: qualitative evaluation of Project ITTREAT - an integrated community hepatitis C service. *Journal of Viral Hepatitis*. pp. 1-12. ISSN 1365-2893

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/85869/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

### **Copyright and reuse:**

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

# **Improving access to care for People Who Inject Drugs: Qualitative evaluation of Project ITTREAT, an integrated community hepatitis C service**

## *Hepatitis C PWID community service*

Clare Phillips<sup>1</sup>, Jasmine Schulkind<sup>2</sup>, Margaret O'Sullivan<sup>1</sup>, Natalie Edelman<sup>3</sup>, Helen Smith<sup>3,4</sup>, Sumita Verma<sup>\*1,2</sup>, Christina Jones<sup>\*5</sup>

\* Joint senior author

<sup>1</sup> Department of Gastroenterology and Hepatology, Brighton and Sussex University Hospital NHS Trust, Brighton UK

<sup>2</sup> Department of Clinical and Experimental Medicine, Brighton and Sussex Medical School, Brighton, UK

<sup>3</sup> Department of Primary Care & Public Health, Brighton & Sussex Medical School, Brighton, UK

<sup>4</sup> Family Medicine and Primary Care, Lee Kong Chian School of Medicine, Nanyang Technological University Singapore, Singapore

<sup>5</sup> School of Psychology, University of Surrey, Guildford, UK

Correspondence to:

Dr Christina Jones

School of Psychology 42AD02

University of Surrey

Guildford

UK

Email: [c.j.jones@surrey.ac.uk](mailto:c.j.jones@surrey.ac.uk)

Telephone: 01483 689436

## **Acknowledgments**

We would like to acknowledge the participants who kindly shared their experiences and the NIHR Research Design Service-South East who helped develop the proposal.

### **Funding statements:**

This work was supported by an educational/research grant from the Brighton and Hove Commissioner and Gilead Sciences (National Gilead Fellowship and Gilead Investigator Sponsored Research IN-UK-337-1981). The funders were not involved in the study design, data collection/analysis or manuscript preparation.

### **Conflicts of interest:**

SV: Research and educational grants/Honorarium from Brighton and Hove Commissioners, Gilead Sciences, AbbVie, Dunhill Medical Trust, the National Institute for Health Research and Kent Surrey and Sussex Deanery

MOS: Travel grants from Gilead

JS, CP, HS, NE, CJ: No conflicts of interest

## **Abstract**

### **Introduction**

Achieving hepatitis C virus (HCV) elimination by 2030 requires an increased linkage to care for people who inject drugs (PWID). Project ITTREAT was established to mitigate barriers to HCV care by providing an integrated service within a local drug and alcohol treatment (DAT) centre.

### **Aim**

This study aimed to explore the experiences of clients and staff involved in Project ITTREAT and assess the facilitators and barriers to a community-based HCV service.

### **Methods**

Between Oct 2014-Apr 2016, DAT attendees were interviewed using one-to-one semi-structured interviews. DAT staff took part in focus groups. All data were recorded, transcribed verbatim and analysed using thematic content analysis.

### **Results**

Fifteen DAT attendees with current/previous HCV infection were interviewed and 15 staff members contributed across two focus groups. DAT staff and attendees reported that Project ITTREAT facilitated access to HCV care by mitigating previous negative hospital-based experiences. Other key facilitators were positive narratives around HCV care and DAT attendees being well engaged in their drug/alcohol recovery. Barriers included a lack of stability in DAT attendees, negative discourse around testing/treatment and stigma associated with attending the DAT to access HCV treatment in some who had successfully achieved drug rehabilitation.

### **Conclusions**

Our findings indicate the positive impact of an integrated and personalised community-based service delivered by a dedicated hepatitis nurse. This played a crucial role in reducing barriers to HCV care for PWID. Our work also highlights areas for future investment including non-DAT based community services and increasing awareness of new treatments amongst this cohort.

## Keywords

*Staff/client experience, substance misuse, Hepatitis C virus, community HCV service, barriers, facilitators*

## Introduction

Hepatitis C virus (HCV) is transmitted by direct blood-blood contact and can cause liver cirrhosis and cancer if left untreated (1). There is currently no effective vaccine. Injecting drug use (IDU) remains the most important risk factor for HCV acquisition and globally 67% of people who inject drugs (PWID) are hepatitis C antibody positive (2).

Globally rates of viral hepatitis deaths (1.4 million/yr) are comparable to those of HIV (1.3 million/yr), malaria (0.5 million/yr) and tuberculosis (1.2 million/yr) (3, 4). After the advent of the highly effective direct acting antivirals (DAA) (5), the WHO launched the Global Health Sector Strategy (GHSS) in 2016, with the aim of eliminating viral hepatitis as a major health burden by 2030 (3). This strategy tasked countries with diagnosing 90% and treating 80% of those with HCV by 2030 (3).

In England, liver disease from HCV infection is a major health burden with approximately 113,000 individuals infected (6). Almost all those with chronic HCV infection in England (92%) have a history of IDU with approximately half of all PWIDs infected (6). In the 2017 Unlinked Anonymous Monitoring (UAM) survey, of those PWIDs aware of their HCV antibody status, 72% reported having ever seen a Hepatologist. Of these, 42% accepted and commenced treatment, 34% declined the offer of treatment and 23% were not offered treatment (7).

Access to DAAs has been gradually rolled out via Operational Delivery Networks (ODNs), led by NHS England (8). Since DAAs first became available in 2014, treatment numbers have increased dramatically in England; from approximately 5100 people receiving HCV treatment annually (2008-2014) to 15, 506 between 2015-2017 (7). However, despite more PWIDs being aware that they have HCV infection (an estimated two thirds now know their status) (7), good evidence of the efficacy of DAAs in PWIDs (9, 10), and low rates of reinfection, the numbers of PWIDs accessing treatment remains low (7, 11-13). The

vulnerable and disenfranchised nature of PWIDs and poor engagement with hospital services undoubtedly contributes to this (14-16).

Barriers to PWIDs accessing HCV treatment have been explored in a number of contexts and are summarised at the patient, provider and national levels in Figure 1 (17). If the UK is to achieve WHO targets, engaging, testing and treating this hard-to-reach cohort is essential. In the UK, intermittent HCV outreach programmes (from hospitals into local drug and alcohol treatment [DAT] services) have been shown to be safe, cost effective, with good uptake and treatment outcomes similar to, and in some cases better than, secondary care (18-21).

In 2013, Project ITTREAT was established within a DAT service and aimed to assess the feasibility of delivering an HCV service in the DAT by collecting real world clinical, patient reported, health economic and qualitative outcomes (17). Here we report on the qualitative study exploring the experiences of DAT clients and staff of Project ITTREAT, assessing the facilitators of and barriers to service use and whether the service provided by Project ITTREAT overcomes recognised barriers to HCV care

## **Methods**

### ***Study setting and intervention background***

Project ITTREAT commenced in Dec 2013 as a two-year project but was subsequently extended for a further six years (until Dec 2021). Interviews and focus groups were all conducted by an experienced qualitative researcher (CJ) between October 2014 and April 2016 as a concurrent embedded qualitative study.

The process of the service set up has been previously described (17). In summary, ITTREAT was located at one of the largest urban DAT service in South East England. A full-time, experienced hepatitis nurse (equivalent to band 7 in the NHS structure) (MOS) (working Monday-Friday) provided blood borne virus (BBV) testing using finger prick dry blood spot testing and hepatitis B virus vaccination to DAT attendees. If qualitative HCV PCR was positive, individuals were contacted (via phone or in person) and offered HCV quantitative PCR/genotype, blood tests, assessment of hepatic fibrosis using a portable FibroScan® 402 (Echosens) (non-fasting) and HCV treatment, at the DAT, under Hepatologist (SV) supervision. Clinics offered were 'one-stop' flexible and run on a 'drop in' basis. All

participants were provided with a contact phone number for the HCV nurse. DAT staff were also trained by the HCV nurse to perform BBV screening. Psychiatric input, opioid substitution therapy (OST), social/peer mentor support and a needle syringe programme were offered onsite by the DAT. The HCV nurse worked closely with other health care professionals both within the community (e.g. GPs and DAT care-co-ordinators) and the hospital-based services (e.g. vascular access team, gastroenterology pharmacy team).

Unique aspects of Project ITTREAT therefore were a dedicated, full-time hepatitis nurse based at the DAT who provided a personalised and holistic service in an integrated manner effectively linking all components of care. Those with ongoing drug and alcohol use were eligible for HCV treatment, as long as they were willing to engage.

### ***Interviewee recruitment***

Study participants included DAT attendees and staff. DAT attendees were eligible if they had been offered and/or were engaged in the HCV service provided there. DAT attendees were purposively sampled to include those who had historically declined, were waiting to start, were currently receiving and who had completed HCV treatment. Interviews were conducted before, during and after DAAs were made available.

All staff based at the DAT (excluding the HCV nurse) were invited to one of the two focus groups where informed consent was taken by the qualitative researcher (CJ). While all staff were invited (by the HCV nurse) to participate in the study, only those available on the dates planned for the focus groups were recruited, utilising a convenience sampling approach.

DAT attendees to the HCV clinic and DAT staff were approached by the HCV nurse, who provided a copy of the participant information sheet and, with their consent, passed their contact details to CJ. Eligible and interested DAT attendees were contacted by CJ to arrange a convenient time for an individual interview, at which time informed consent was taken

Interviews (for HCV clinic attendees) and focus groups (for DAT staff) took place in a private room within the DAT service.

### ***Data collection***

The interviews and focus groups were semi-structured, with the interviewer following a topic guide (see supplementary information). Interviews with DAT attendees lasted

between 30 -60 minutes and topics included history of IDU, experience of initial HCV diagnosis, barriers and motivators to engaging in HCV testing and treatment, experiences of other healthcare services including in the community and areas of future service improvement. Each focus group lasted an hour and included topics such as the challenges in HCV testing and treatment uptake, experiences of hospital and community-based services and areas of future service improvement.

### ***Data analysis***

Transcripts from DAT attendee interviews were analysed first. Staff focus group transcripts were incorporated into the analysis once completed. Thematic content analysis was performed using Burnard's 14-stage method (22). To begin with the verbatim transcripts were coded openly to generate as many themes as possible. The themes that emerged were partly deductive, reflecting the research objectives, and partly inductive emerging during data familiarisation. A thematic framework was then constructed. To ensure reliability, data were initially analysed by JS, the themes were then compared and discussed with CJ, to develop an overall analytical framework for the DAT attendee interviews and DAT staff focus groups.

### ***Ethical approval***

Ethical approval for the study was obtained (NRES Committee East Midlands - Derby REC ref 13/EM/0275). All participants gave signed, informed consent.

## **Results**

Tables 1 and 2 show demographic and additional data of DAT clients interviewed and staff that took part in the focus groups. The DAT clients entirely described themselves as white (100%), males (80%) with 40% aged 35-44 yrs and 40 % aged 45-54 yrs. Overall 7 (47%) were currently unemployed. All were either past (n=12) or current (n=3) PWID. Two had completed successful addiction rehabilitation, for the remaining recovery was ongoing. Overall 9 (60%) had either already completed or were currently receiving HCV treatment. Of the 15 interviews, 11 were conducted from 2014-15 during the transition from interferon to DAA based regimens, with the remaining



completed in 2016. The majority of clients interviewed had received/were receiving interferon-based HCV treatment (7/9, 78%).

Fifteen staff members took part in the focus groups, equally split amongst males and females (seven and eight respectively). The majority, 10 (75%), were aged 45-54 yrs with 14 (93%) describing themselves as white. Duration of employment at the DAT ranged from 1 - 20 years.

**Table 1 - Demographics of DAT attendees**

**Table 2 - Demographics of DAT staff**

**Facilitators of accessing HCV care via Project ITTREAT**

This comprised 4 principal themes and 15 sub-themes (figure 2)

**1) Trusting client-provider relationships**

The close relationship between clients and their keyworker/care-coordinator at the DAT was clear from the interviews and focus groups. This relationship acted as an entry point into HCV care; staff described initiating discussions around HCV care and then referring clients to the on-site hepatitis nurse once they were ready to engage. Interestingly, staff perceived themselves as 'sellers' of HCV care.

*"Well it's down to us to sell it isn't it [HCV testing and treatment]? Because if we don't sell it, it won't happen. It's basically that." (DAT Staff member, focus group 1)*

The relationship between clients and the HCV nurse was central to their engagement with Project ITTREAT. Participants valued the 'non-judgemental', 'personal' and 'friendly' approach of the HCV nurse. The interviews highlighted the importance of a holistic and personalised approach when engaging clients; the HCV nurse supported clients' housing applications and mental health needs as well as their HCV treatment.

*"I mean, I have to say I think [HCV Nurse] is one of the main people behind and she's, she's so friendly and nice that she just puts you at ease anyway. There's not like, you're not dealing with fearful doctors with a sense of impending doom on all sides."*  
(Participant 3, 20 months since diagnosis, untreated)

Importantly, despite poor engagement with health services, for two participants a trusting relationship with their GP facilitated entry into HCV care.

*“I’d prefer to be seen at the doctors...the GP I’ve got now, yeah, she’s really she’s brilliant...Yeah, many a time I’ve gone to the surgery and I’ve been in there twenty minutes half an hour, just emptying, emptying in front of her. And she’s really good, she listens”*

(Participant 15, 11 years since diagnosis, completed treatment)

The focus groups also highlighted the importance of the close relationship between DAT staff and the HCV nurse, facilitating a greater awareness of HCV within the service.

*“Having someone here in the building just makes a huge difference; to be able to ask questions and get information about Hepatitis when people ask things. It just raises, I think all of our kind of awareness of it.”* (DAT Staff member, focus group 1)

### **Hepatitis C care as part of the recovery pathway**

Both clients and staff perceived HCV treatment as the natural, next step in the recovery pathway. Successful recovery from drug and alcohol addiction empowered clients to seek HCV treatment.

*“When people have gone into residential, and then one of their next goals that people often have, is when they leave residential, is then to address their hepatitis issues.”* (DAT staff member, Focus group 1)

*“When I got myself clean and thought to myself; now or never. You never know what could happen, in the future. While I’m headstrong at the minute; I’ll just go for it.”*

(Participant 4, 7 years since diagnosis, on treatment)

HCV infection was inextricably linked to drug use; once stable in addiction recovery, participants expressed a desire to disassociate themselves from the stigma attached to HCV infection.

*“I suppose some of it ties into the stigma again, you know I wanted to be clear and, you know, as free from anything drug-related...as quickly as possible.”* (Participant 1, 4

years since diagnosis, completed treatment)

Following recovery, participants expressed both a greater awareness of the health impacts of untreated HCV and a heightened sense of their own mortality. Without withdrawal

symptoms, clients were more likely to attribute their physical symptoms to HCV, which acted as a motivator to seeking treatment.

*"I didn't want to have hepatitis, I don't wanna die young, do you know what I mean. Like, I've had it for a long time, and you know, I don't, like, I'm only like 49 now or 48, something like that. But, like, I'm not old, do you know what I mean, and I'm not young- I'm middle aged. So I wanna, I'd love to have some time without the hepatitis, I'd love to get it out of me body cos I've seen someone die of hepatitis and it's not very nice."* (Participant 5, 15 years since diagnosis, completed treatment)

One client reported not having understood the seriousness of HCV until he engaged with the DAT and the recovery process.

*"I didn't really understand the seriousness of Hep C till I started like seeing...someone at the [DAT] about it and then I got linked in with [HCV nurse]. I started realising this isn't something you can just shrug off like I've done for ten years.."* (Participant 12, 10 years since diagnose, 10 weeks into treatment)

## **2) Mitigation of previous negative experiences of secondary care**

Clients expressed reluctance to engage in hospital-based health services, for both their general health and for HCV treatment, but Project ITTREAT mitigated many of these issues for clients and staff. Mistrust, fear and bad experiences of hospitals were widely reported:

*"I don't like hospitals. I only ever go to hospital if I'm dying."* (Participant 11, 6 years since diagnosis, untreated)

*"It's the association as well, I think for our client group as well being in hospital- you know a lot of negative experiences: you know memories of overdosing and nearly dying."* (DAT staff members, focus groups 2)

*"And you do hear people talking about their bad experiences: feeling judged up at A&E. I think self-worth and self-esteem has got a lot to do with going up to the hospital: 'I'm not worthy of their time', 'these other people are- mine's self-inflicted', 'why should they care about me?'"* (DAT staff member, focus group 1)

Being able to access HCV care without having to attend the hospital-based services was positively welcomed:

*“Down here’s better I think: cos it’s all in one place. You know, it’s all- it’s all in the one building. Instead of being up here and then you’ve gotta come down here and then you’ve gotta go there and then here; things’ll get confused” (Participant 7, 1 year since diagnosis, untreated)*

[Talking about hospital service] *“Much, much more medicalised, much more; this feels much more community orientated. Um, you know, there nurses felt like nurses and...yeah it was going to hospital, you know and having your regular appointment at the hospital...I mean it felt like that”. (Participant 8, 4 years since diagnosis, untreated)*

Hospital-based bureaucracy emerged as an important system-level barrier, especially the inconvenience of travelling to hospital, inflexibility of appointment times and lengthy appointment waits. These were overcome by the flexible approach adopted by ITTREAT:

*“If you’re being seen in outpatients at the [Hospital] and you miss an appointment- that’s it. Whereas with [HCV nurse] she’ll call you again and again and you can have three goes before you see her. Whereas with the [Hospital] they have an appointment system that doesn’t work like that.” (DAT staff member, focus group 1)*

*“I thought it was a little less, err, impersonal. You just feel like you’re a cow being forced through, like a sheep dip kind of system in hospitals. But here you know they know your name and they’re a little bit more personal with you. I think a little bit more caring cos they have a little bit more time” (Participant 2, 1 year since diagnosis, on treatment)*

Staff members also described a lack of coordinated care between hospital Hepatology services and the DAT which Project ITTREAT helped alleviate:

*“It’s communication as well: [The hospital department] wouldn’t necessarily have all the facts to hand, whereas [HCV nurse] can speak to care coordinators on a one to one” (DAT staff member, focus groups 1)*

### **3) Positive narratives of HCV care**

Clients and staff members discussed the influence of ‘word of mouth’ stories of HCV treatment from peers within the recovery community. Traditionally, negative stories have dissuaded clients from seeking treatment, but positive narratives encourage participants to engage in care, especially, clients’ experiences with DAAs.

*“[HCV nurse] was just saying- she’s had an uptake in Scottish people- cos they know each other in the community and cos one of them has had the treatment with [HCV nurse]: now she’s had one or two people from the same little social circle turning up.*

*And yeah so, it is word of mouth”* (DAT staff member, focus group 1)

*“It’s just general, you just sit and talk, but everybody’s raving about this new stuff, everybody claims that ‘oh I know someone that’s done it’.”* (Participant 14, 6 years since diagnosis, on treatment)

*“I found out about the new treatment that’s available, and thought I’d wait. And then I forgot about it; conveniently shoved it in that place that you don’t think about it, and [Hepatitis C nurse] called me and said, ‘do you wanna go up for a trial on this?’ So were just waiting to hear... I think it’s here, well it’s through [Hepatitis C nurse] - she’d be able to tell you and it’s the shorter treatment and it doesn’t have the depression side effects. And to be honest I’d wait years for that treatment, rather than take the risk of having the negative side effects...”* (Participant 3, 20 months since diagnosis, untreated)

### ***Barriers to accessing HCV care via Project ITTREAT***

This comprised of 3 principal themes and 8 sub-themes (figure 3)

#### **1) Lack of stability**

The notion of instability emerged as a central theme in preventing participants from accessing HCV treatment whereby social circumstance competed with health needs. This included homelessness or lack of permanent accommodation, unemployment, and time spent in prison:

*“But because erm, my life was just chaos at the time- I was homeless, I was trying to hold down a job and...yeah it was just sort of really impossible for me to kind of have enough consistency to start doing the treatment”* (Participant 2, 1 year since diagnosis, on treatment)

*“I think accommodation, people’s stability around accommodation and things like that: having to have a fridge, you know, a personal space, that sort of thing. Having somewhere where it’s safe to have a parcel to be delivered”* (DAT staff member, focus group 1)

Furthermore, emotional instability due to complex mental health problems, lack of strong social networks and, in particular, ongoing drug and alcohol use were perceived to be a key factor in determining clients’ stability to engage in treatment.

*“It’s not your first priority. Your first priority when you’re out there is to score more drugs. Comes above and before everything. So getting rid of a blood borne virus which you might catch the next day anyway...fighting a losing battle.”* (Participant 11, 6 years since diagnosis, untreated)

*“I think lots of people that are homeless on the streets, there’s this almost, I can only think of one word and its cavalier. You know, ‘I know I’ve got Hep C but you know: what’s the point? I’m using all these drugs.’ Just to manage my situation in the here and now. And you know, treatment options are way down their list of priorities really.”* (DAT staff member, focus group 1)

## **2) Stigma**

Stigma, relating to HCV diagnosis, led to an initial reluctance among participants to accept the diagnosis and therefore a delay in accessing information and treatment. Before engaging with the community service, participants reported very little knowledge of the health consequences of HCV. Interviewees also described their unwillingness to disclose their diagnosis to friends, family members and partners.

*I haven’t told anyone about it [HCV]. Cos I’m frightened of the stigma comin back, do you know what I mean?* (Participant 5, 15 years since diagnosis, completed treatment)

One important barrier to engagement with Project ITTREAT that emerged was the stigma associated with the physical premises of the DAT. This was particularly evident amongst

participants who were stable in recovery, no longer perceiving themselves as “drug addicts”. This led some participants to express their preference for a separate, non-DAT-based community HCV service.

*“Yeah, I used to have that a lot, kind of walking up the steps at the traffic lights and there are kind of loads of cars, kind of gridlock, and you know you’re almost advertising yourself as like an addict walking up the steps.”* (Participant 13, 2 year since diagnosis, completed treatment)

*“I think it would be better if they had just a hepatitis place that they concentrate on hepatitis. And then you’ve got your drug place, where you go for your methadone, and all that. I think it should be, like, separate...”* (Participant 5, 15 years since diagnosis, completed treatment)

### **3) Negative discourse around testing and treatment**

Participants described negative anecdotes from their peers, of hepatitis testing and treatment revolving around risk of substance misuse relapse, interferon related physical and mental side effects, length of the treatment course and need for liver biopsies.

*“well yeah, getting tested like with the biopsy thing, cos I was told some quite nasty things that it gets stuck right into you and it has to cut a bit of your liver out and it’s like...yeah it seems sort of like quite painful and quite horrible really.”* (Participant 10, 8 years since diagnosis, untreated)

[Discussing the risk of relapse] *“I really don’t wanna take interferon. I really am absolutely petrified of it. Because I’ve, over the last 18 months I’ve built up so much of a normal life. My children talk to me as though it never happened...I cannot rock that boat.”* (Participant 3, 20 months since diagnosis, untreated)

*“Yeah, and its side effects, cos back then as well it was all interferon and people were telling me it’s like chemotherapy: you’re gonna lose your hair and all sorts. And I was thinking, I don’t feel ill- I’m not putting myself through all that”* (Participant 14, 6 years since diagnosis, on treatment)

## Discussion

This qualitative evaluation of Project ITTREAT highlights how our community hepatitis clinic successfully facilitated DAT attendees to access HCV treatment, removing barriers, specifically those at the provider level (figure 1). The presence of a dedicated provider, positive narratives of HCV treatment from peers and stability within drug/alcohol recovery were all important facilitators and motivators that enabled DAT attendees to address their HCV diagnosis and access treatment. Lack of personal stability, negative stories from peers about HCV treatment and stigma remained important barriers to accessing HCV care, despite our intervention. An unanticipated barrier for those who had graduated from drug use and OST treatment was the stigma generated by locating the community hepatitis clinic within the DAT.

The time period for this qualitative study (Oct 2014 - Apr 2016) spanned the transition from interferon-based treatments to combinations of interferon and DAAs and finally interferon-free DAA regimens. The facilitators and barriers identified therefore reflect this whole time period. Most facilitators related to project ITTREAT itself (trusting client provider relationship, HCV care as part of recovery process, mitigation of previous negative experiences of secondary care) while others such as the theme 'positive narratives of HCV care' are reflective of both project ITTREAT and the newer treatments, as these are inextricably linked. Negative discourse around HCV treatment largely related to the older treatments and liver biopsies, whilst stigma attached to the clinic location, the DAT, was specific to the ITTREAT project. Stigma of HCV and lack of stability to engage with HCV treatment were general barriers reported in this cohort, not specific to either project ITTREAT or the changing treatment landscape.

A flexible, trusting client-provider relationship helped alleviate patient and provider level barriers and was central to DAT attendees engaging with Project ITTREAT. This finding closely mirrors those reported previously (19, 23, 24). The importance of this flexible approach to delivering HCV care to PWIDs cannot be underestimated. Particularly noted was the central relationship between the HCV nurse and DAT attendees, which was crucial in client engagement, as also observed by others (24). Being located in the DAT full-time also allowed for close working relationships between the HCV nurse and DAT staff, enabling



effective working relationships and more holistic provision of care for clients in drug and alcohol recovery. This not only raised awareness and the profile of HCV amongst DAT staff but also enabled the adoption of a 'shared-care' approach and smooth referral between services. In summary, these relationships, and the removal of bureaucratic barriers allowing for flexible working, created an accessible environment for DAT attendees to engage with Project ITTREAT. These findings are corroborated by the ETHOS study, which found that an engaged clinician and accessible treatment pathway were key facilitators of engagement (16).

However, while studies have shown that community-based interventions result in an increase in HCV treatment, overall treatment uptake remains low (25-27). This could be partly related to lack of co-location of HCV screening and treatment, inflexible clinic timings and not involving peer mentors (25-27). ITTREAT provided an integrated test and treat service with "drop in clinics" where PWID engaged with the same nurse. In the absence of interferon or liver biopsies as barriers to treatment, we anticipate our model of care delivery provides an unprecedented opportunity to increase treatment uptake in this cohort in the era of DAAs.

Lack of stability emerged as a major barrier to HCV care and has been reported elsewhere (14, 23, 24). This included physical instability (such as housing), psycho-social instability and in particular drug and alcohol use. Accessing HCV care became a priority once stability was achieved, including those who were on the recovery pathway. The intention to address health issues once in recovery has also been reported in a study evaluating the barriers to PWIDs accessing sexual health services (28). Thus, by placing health services at the DAT, as in Project ITTREAT, services are perfectly placed to respond in a timely manner to clients who are ready to engage with HCV (and other health) care during their recovery. This was described as 'timeliness' by Harris in 2018 and appears to be a generalizable finding (24). Identifying these time points and developing an accessible service for clients has the potential to improve health outcomes in this cohort.

The stigma perceived by PWID remains an important barrier to accessing HCV care (29). This could be at a personal level (related to drug use) or the discriminatory attitude of health care providers (30, 31). This is often coupled with limited education amongst clinicians regarding addiction (29). In addition a novel finding from our study revealed the distinct and

contrasting attitudes towards the DAT. Whilst some who had graduated from drug use felt attending the DAT and integrating with others who were in the early stages of recovery, reinforced their successful recovery, others felt it put them at risk of relapse and of being unable to escape the label of a 'drug addict'. This stigma around engagement with the DAT was identified previously in a 2012 WHO study (23). It must therefore be acknowledged that "one size does not fit all", and the emphasis should be on the provision of personalised care. As suggested by some participants, stigma of the DAT could be overcome by offering an HCV service in a 'half-way house' somewhere between the hospital and DAT. This was the main area of potential service improvement identified by participants. Some DAT attendees reported strong relationships with their GP and reported a preference for the anonymity a GP surgery provides. There is a growing body of literature demonstrating that HCV treatment can be effectively delivered through primary care, with or without OST services (14, 19, 32). This is thus a useful and potentially important avenue for future service development.

Additionally, stories shared within the substance misuse community shaped participants' perceptions of HCV testing and treatment. While negative stories were reported in this study, these largely referred to the now obsolete interferon-based treatment and liver biopsies. At the time of this study, HCV treatment was transitioning from interferon-based treatment to DAAs (the majority of the interviewees received interferon-based regimens), thus discourse on the new DAAs was limited. Importantly, these peer networks also disseminated positive narratives around HCV treatment, motivated others to access care and some participants reported hearing positive stories of the new DAAs via the recovery community. Previous research has identified the influence of 'word of mouth' stories among populations of PWIDs (16, 33, 34) and increasing evidence in the literature supports a role for peer mentors in improving treatment knowledge and uptake (27, 35-37). With the introduction of the *FibroScan*<sup>®</sup> for non-invasive assessment of hepatic fibrosis and better tolerated pan-genotypic DAAs there is an opportunity to harness the influence of peer networks to dispel the negative discourse around HCV testing and treatment.

Finally, concerns regarding reinfection remains a barrier to initiating HCV treatment amongst PWID, particularly for clinicians. However as shown by others (10, 38, 39) reinfection rates remain low in PWID (< 3/100 person years) especially if there is timely

introduction of opioid substitution therapy. This again emphasises the importance of integrated services when engaging PWID in HCV treatment.

This study had limitations. Participants were initially approached by the HCV nurse who was the principal clinician running Project ITTREAT at the DAT. Loyalty to the nurse may have biased responses and may have, inadvertently, led to selective recall. Secondly, the client's perspective comes only from DAT attendees of Project ITTREAT, and therefore excludes the experiences of DAT attendees not engaged in the HCV treatment service provided by the project. Thirdly, DAT staff volunteered to take part in the focus groups, potentially self-selecting those with the greatest interest or strongest views on HCV services, and again potentially clouding responses. Additionally, only staff able to attend on the days of the focus groups were recruited, possibly introducing bias. Furthermore, data collection took place within the DAT which may have resulted in a potential reporting bias in interview responses, although the qualitative researcher was independent to the DAT. Finally, since most participants were in recovery and received interferon-based treatment, we were unable to assess in detail the impact of recovery status and the advent of DAAs on attitudes and perceptions amongst clients and staff. This study was conducted in one geographical region of the UK; however, its findings are corroborated by observations from other national and international studies (16, 24).

Future research needs to focus on how best to encourage collaborative working between DAT and hepatology communities; raise the profile of community models of care to enable national adoption; eliminate the still persisting stigma towards PWID; effectively educate PWID and healthcare providers about DAAs; dispel antiquated myths about older treatments and liver biopsies and, finally, investigate how or where a 'half-way house' HCV clinic may be best located.

In summary this study illustrates the barriers and facilitators amongst DAT staff and attendees of a community HCV service embedded within a DAT. This has important implications for policy makers and regional ODNs tasked with allocating resources to achieve HCV elimination. HCV treatment as part of drug and alcohol recovery pathways is now feasible, particularly in light of the new safe and effective DAAs that are increasingly available. If HCV elimination is to be achieved, engaging PWID in care by a movement

towards community-based services, and away from historic hospital-based settings is essential.

## References

1. World Health Organisation. Hepatitis C [internet]. Updated 2019. Accessed 6/8/19. Available from: <https://www.who.int/news-room/fact-sheets/detail/hepatitis-c>.
2. Nelson PK, Mathers BM, Cowie B, Hagan H, Des Jarlais D, Horyniak D, et al. Global epidemiology of hepatitis B and hepatitis C in people who inject drugs: results of systematic reviews. *Lancet*. 2011;378(9791):571-83.
3. World Health Organisation. Global Health Sector Strategy On Viral Hepatitis 2016–2021. 2016 [internet]. Accessed 6/8/19. Available from: <https://apps.who.int/iris/bitstream/handle/10665/246177/WHO-HIV-2016.06-eng.pdf;jsessionid=6A38663530EAB3FC3DBFDF9E07D4F683?sequence=1>
4. World Health Organization. Combating Hepatitis B And C To Reach Elimination By 2030. Geneva; 2016 [internet]. Accessed 6/8/19. Available from: [https://apps.who.int/iris/bitstream/handle/10665/206453/WHO\\_HIV\\_2016.04\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/206453/WHO_HIV_2016.04_eng.pdf?sequence=1)
5. Asselah T, Marcellin P, Schinazi RF. Treatment of hepatitis C virus infection with direct-acting antiviral agents: 100% cure? *Liver Int*. 2018;38 Suppl 1:7-13.
6. Harris HE, Costella A, Harris R, Mandal S and contributors. Hepatitis C in England, 2019 report: Working to eliminate hepatitis C as a major public health threat. April, 2019 [internet]. Public Health England, London. Accessed 6/8/19. Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/798270/HCV\\_in-England\\_2019.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/798270/HCV_in-England_2019.pdf)
7. Public Health England. Hepatitis C in England 2018 Report. 2018 [internet]. Accessed 6/8/19. Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/732469/HCV\\_IN\\_THE\\_UK\\_2018\\_UK.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/732469/HCV_IN_THE_UK_2018_UK.pdf)
8. NHS England. Clinical Commissioning Policy Statement: Treatment of chronic Hepatitis C in patients with cirrhosis. 2015 [internet]. Accessed 6/8/19. Available from: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/06/hep-c-cirrhosis-policy-statmnt-0615.pdf>
9. Grebely J, Dalgard O, Conway B, Cunningham EB, Bruggmann P, Hajarizadeh B, et al. Sofosbuvir and velpatasvir for hepatitis C virus infection in people with recent injection drug use (SIMPLIFY): an open-label, single-arm, phase 4, multicentre trial. *Lancet Gastroenterol Hepatol*. 2018;3(3):153-61.
10. Dore GJ, Altice F, Litwin AH, Dalgard O, Gane EJ, Shibolet O, et al. Elbasvir-Grazoprevir to Treat Hepatitis C Virus Infection in Persons Receiving Opioid Agonist Therapy: A Randomized Trial. *Ann Intern Med*. 2016;165(9):625-34.
11. Weir A, McLeod A, Innes H, Valerio H, Aspinall EJ, Goldberg DJ, et al. Hepatitis C reinfection following treatment induced viral clearance among people who have injected drugs. *Drug Alcohol Depend*. 2016;165:53-60.
12. Zeremski M, Zibbell JE, Martinez AD, Kritz S, Smith BD, Talal AH. Hepatitis C virus control among persons who inject drugs requires overcoming barriers to care. *World J Gastroenterol*. 2013;19(44):7846-51.
13. Childs E, Assoumou SA, Biello KB, Biancarelli DL, Drainoni ML, Edeza A, et al. Evidence-based and guideline-concurrent responses to narratives deferring HCV treatment among people who inject drugs. *Harm Reduct J*. 2019;16(1):14.
14. Charlebois A, Lee L, Cooper E, Mason K, Powis J. Factors associated with HCV antiviral treatment uptake among participants of a community-based HCV programme for marginalized patients. *J Viral Hepat*. 2012;19(12):836-42.

15. Marufu M, Williams H, Hill SL, Tibble J, Verma S. Gender differences in hepatitis C seroprevalence and suboptimal vaccination and hepatology services uptake amongst substance misusers. *J Med Virol.* 2012;84(11):1737-43.
16. Treloar C, Rance J, Dore GJ, Grebely J, Group ES. Barriers and facilitators for assessment and treatment of hepatitis C virus infection in the opioid substitution treatment setting: insights from the ETHOS study. *J Viral Hepat.* 2014;21(8):560-7.
17. Hashim A, O'Sullivan M, Williams H, Verma S. Developing a community HCV service: project ITTREAT (integrated community-based test - stage - TREAT) service for people who inject drugs. *Prim Health Care Res Dev.* 2018;19(2):110-20.
18. Selvapatt N, Ward T, Harrison L, Lombardini J, Thursz M, McEwan P, et al. The cost impact of outreach testing and treatment for hepatitis C in an urban Drug Treatment Unit. *Liver Int.* 2017;37(3):345-53.
19. Wade AJ, Veronese V, Hellard ME, Doyle JS. A systematic review of community based hepatitis C treatment. *BMC Infect Dis.* 2016;16:202.
20. Jack K, Willott S, Manners J, Varnam MA, Thomson BJ. Clinical trial: a primary-care-based model for the delivery of anti-viral treatment to injecting drug users infected with hepatitis C. *Aliment Pharmacol Ther.* 2009;29(1):38-45.
21. Pourmarzi D, Hall L, Hepworth J, Smirnov A, Rahman T, FitzGerald G. Clinical effectiveness, cost effectiveness and acceptability of community-based treatment of hepatitis C virus infection: A mixed method systematic review. *J Viral Hepat.* 2019;26(4):432-53.
22. Burnard P. A method of analysing interview transcripts in qualitative research. *Nurse Educ Today.* 1991;11(6):461-6.
23. World Health Organization. Barriers and facilitators to hepatitis C treatment for people who inject drugs. 2012 [internet]. Accessed 6/8/19. Available from: <http://www.euro.who.int/en/health-topics/communicable-diseases/hepatitis/publications/2012/barriers-and-facilitators-to-hepatitis-c-treatment-for-people-who-inject-drugs.-a-qualitative-study>
24. Harris M, Bonnington O, Harrison G, Hickman M, Irving W, team H. Understanding hepatitis C intervention success-Qualitative findings from the HepCATT study. *J Viral Hepat.* 2018;25(7):762-70.
25. Crowley D, Cullen W, Laird E, Lambert JS, Mc Hugh T, Murphy C, et al. Exploring Patient Characteristics and Barriers to Hepatitis C Treatment in Patients on Opioid Substitution Treatment Attending a Community Based Fibro-scanning Clinic. *J Transl Int Med.* 2017;5(2):112-9.
26. Harrison GI, Murray K, Gore R, Lee P, Sreedharan A, Richardson P, et al. The Hepatitis C Awareness Through to Treatment (HepCATT) study: improving the cascade of care for hepatitis C virus-infected people who inject drugs in England. *Addiction.* 2019;114(6):1113-22.
27. Keats J, Micallef M, Grebely J, Hazelwood S, Everingham H, Shrestha N, et al. Assessment and delivery of treatment for hepatitis C virus infection in an opioid substitution treatment clinic with integrated peer-based support in Newcastle, Australia. *Int J Drug Policy.* 2015;26(10):999-1006.
28. Edelman NL, Patel H, Glasper A, Bogen-Johnston L. Understanding barriers to sexual health service access among substance-misusing women on the South East coast of England. *J Fam Plann Reprod Health Care.* 2013;39(4):258-63.
29. Chan Carusone S, Guta A, Robinson S, Tan DH, Cooper C, O'Leary B, et al. "Maybe if I stop the drugs, then maybe they'd care?" -hospital care experiences of people who use drugs. *Harm Reduct J.* 2019;16(1):16.
30. Lloyd C. The stigmatization of problem drug users: A narrative literature review. *Drugs: Education, Prevention and Policy.* 2013;20(2):85-95.

31. Mincin J. *Addiction and Stigmas: Overcoming Labels, Empowering People in New Directions in Treatment, Education, and Outreach for Mental Health and Addiction*: Springer; 2018. P125-131
32. Newman AI, Beckstead S, Beking D, Finch S, Knorr T, Lynch C, et al. Treatment of chronic hepatitis C infection among current and former injection drug users within a multidisciplinary treatment model at a community health centre. *Can J Gastroenterol*. 2013;27(4):217-23.
33. Swan D, Long J, Carr O, Flanagan J, Irish H, Keating S, et al. Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration. *AIDS Patient Care STDS*. 2010;24(12):753-62.
34. Jordan AE, Masson CL, Mateu-Gelabert P, McKnight C, Pepper N, Bouche K, et al. Perceptions of drug users regarding hepatitis C screening and care: a qualitative study. *Harm Reduct J*. 2013;10:10.
35. Crawford S, Bath N. Peer support models for people with a history of injecting drug use undertaking assessment and treatment for hepatitis C virus infection. *Clin Infect Dis*. 2013;57 Suppl 2:S75-9.
36. Norman J, Walsh NM, Mugavin J, Stoové MA, Kelsall J, Austin K, et al. The acceptability and feasibility of peer worker support role in community based HCV treatment for injecting drug users. *Harm Reduct J*. 2008;5:8.
37. Henderson C, Madden A, Kelsall J. 'Beyond the willing & the waiting' - The role of peer-based approaches in hepatitis C diagnosis & treatment. *Int J Drug Policy*. 2017;50:111-5.
38. Rossi C, Butt ZA, Wong S, Buxton JA, Islam N, Yu A, et al. Hepatitis C virus reinfection after successful treatment with direct-acting antiviral therapy in a large population-based cohort. *J Hepatol*. 2018;69(5):1007-14.
39. Simmons B, Saleem J, Hill A, Riley RD, Cooke GS. Risk of Late Relapse or Reinfection With Hepatitis C Virus After Achieving a Sustained Virological Response: A Systematic Review and Meta-analysis. *Clin Infect Dis*. 2016;62(6):683-94.

<b>Patient Level</b> <ol style="list-style-type: none"> <li>1. Majority are PWID with poor engagement with secondary care due to chaotic lifestyle and competing priorities</li> <li>2. Asymptomatic nature of the disease</li> <li>3. Perceived stigmatisation and prior negative experiences with health services</li> <li>4. Myths associated with antiviral treatment and liver biopsy</li> </ol>
<b>Provider level</b> <ol style="list-style-type: none"> <li>1. Failure to understand complex needs of PWID</li> <li>2. Lack of awareness, hence not a priority for health care professionals</li> <li>3. Bureaucratic and inflexible hospital environment</li> <li>4. Prejudice and reluctance to treat those with ongoing alcohol and drug use</li> <li>5. Misconceptions regarding treatment efficacy and reinfection in PWID</li> <li>6. Lack of multidisciplinary approach with suboptimal interactions between addiction specialists and Hepatologists</li> </ol>
<b>National level</b> <ol style="list-style-type: none"> <li>1. Restricted access to antiviral drugs</li> <li>2. Lack of accurate data on HCV epidemiology</li> </ol>

**Figure 1** Barriers to care in individuals/PWID with hepatitis C virus infection (14)

**Table 1 - Demographics of DAT attendees**

ID	Age/ Gender	Injecting status	Addiction rehab	Employment status	Occupation	Ethnicity	Years since HCV diagnosis
001	35-44 M	Ex PWID	Ongoing	Student	P/T Youth offending service	White	4
002	45-54 M	Ex PWID	Ongoing	FT	Painter	White	1
003	35-44 F	Ex PWID	Completed	Homemaker	(previously chef)	White	20 months
004	25-34 M	Current PWID	Ongoing	Unemployed	(previously chef)	White	7
005	45-54 M	Ex PWID	Ongoing	Not in paid employment due to disability		White	15-20
006	45-54	Ex PWID	Ongoing	Unemployed	(previously TEFL	White	2



	M				teacher)			
007	35-44 M	Ex PWID	Ongoing	Other	Big Issue seller	White	1	
008	45-54 F	Current PWID	Ongoing	Not in paid employment due to sickness	(previously social worker)	White	4	
009	25-34 M	Ex PWID	Ongoing	FT	Scaffolder	White	5	
010	35-44 M	Ex PWID	Ongoing	Other	Voluntary worker	White	8	
011	25-34 M	Ex PWID	Ongoing	Other	Voluntary worker	White	6	
012	35-44 M	Ex PWID	Ongoing	Other	Intern – support worker (drug & alcohol services)	White	10	
013	35-44 M	Ex PWID	Completed	Unemployed		White	2	
014	45-54 F	Current PWID	Ongoing	Unemployed		White	6	
015	45-54 M	Ex PWID	Ongoing	Unemployed	(previously roofer)	White	11	

\*Abbreviations: F/T = full time, P/T = part time, PWID = person who injects drugs, TEFL = teaching English as a foreign language, PEG IFN = pegylated interferon, RBV = Ribavirin, SOF = Sofosbuvir, DAC = Daclatasvir, N/A = not applicable.

**Table 2 - Demographics of DAT staff**

ID	Age	Gender	Employment status	Job title	Duration employed at DAT (years)	Ethnicity
001	45-54	F	FT	Community nurse	14	White
002	35-44	F	FT	Community nurse	2	White
003	45-54	M	FT	Engagement and recovery worker	>10	White
004	45-54	F	FT	Senior community practitioner nurse	8	White
005	45-54	F	PT	Community nurse	1	White
006	45-54	M	FT	Community charge nurse	9	White
007	35-44	M	FT	Community charge nurse	11	White
008	55-64	M	FT	Engagement and recovery worker	14	Other
009	25-34	F	Other – bank staff	Community nurse	>1	White
010	45-54	M	PT	Drug and alcohol care coordinator	1 ½	White
011	55-64	F	FT	Community nurse	5	White
012	45-54	F	PT	Community charge nurse	20	White
013	45-54	M	FT	LGBT support worker	5	White
014	45-54	F	PT	Community charge nurse	10	White
015	45-54	M	FT	Care co-ordinator	2 ½	White

\* F/T = full time, P/T = part time

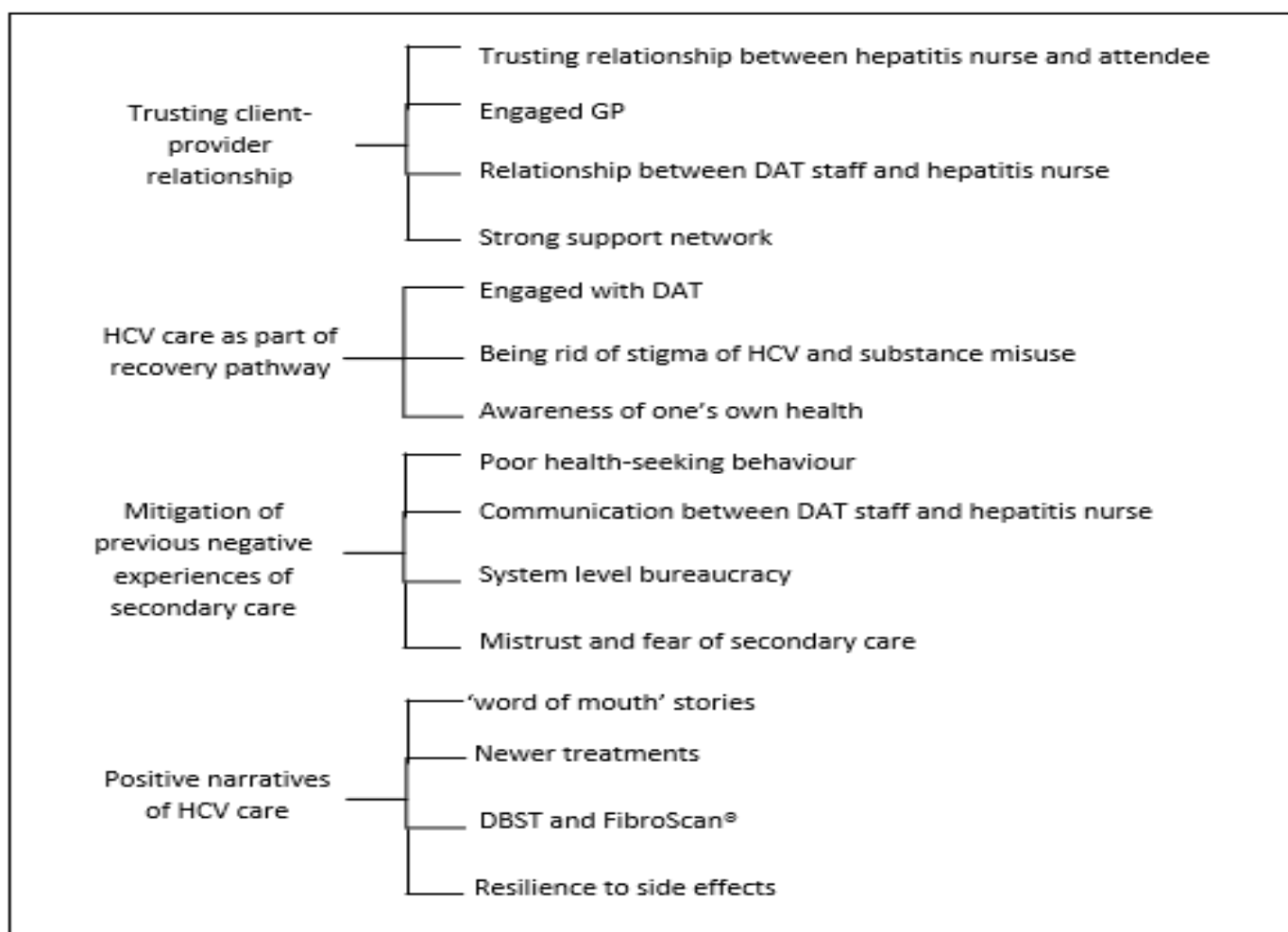


Figure 2. Facilitators of accessing treatment and testing via ITTREAT project. Major headings relate to the principal themes, and the right-hand column the subthemes.

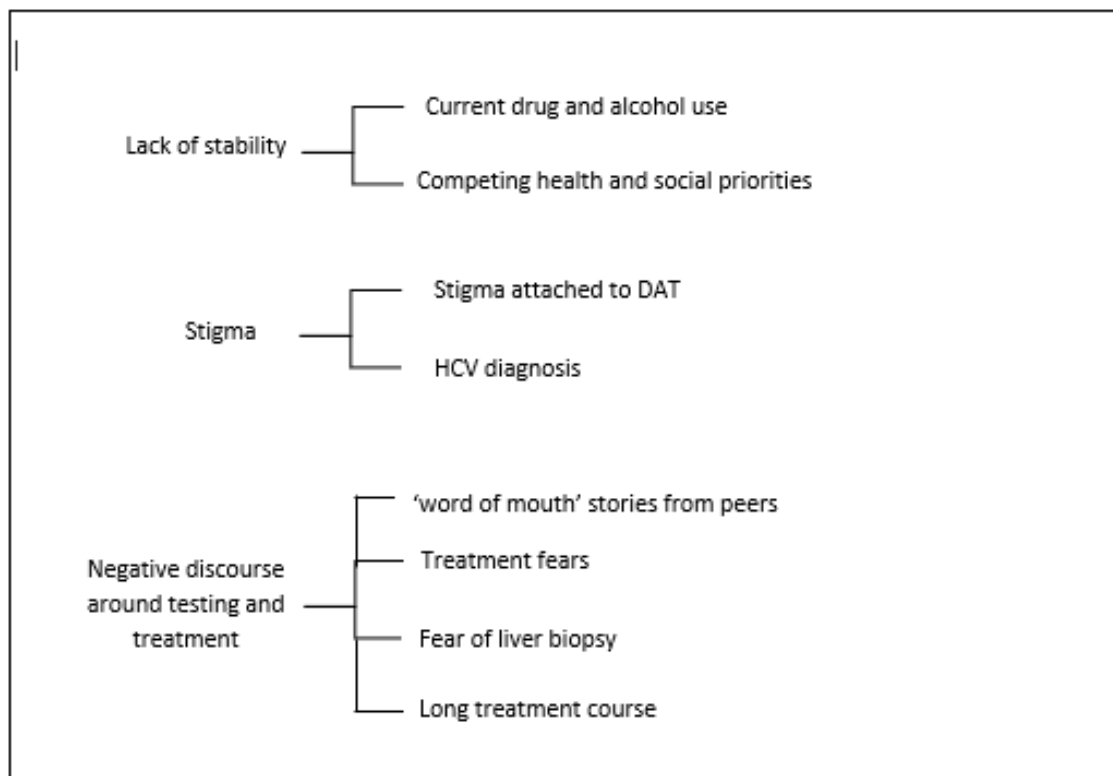


Figure 3. Barrier to accessing treatment and testing via ITTREAT project. Major headings relate to the principal themes, and the right-hand column the subthemes.